Statement of Brent Smith

Mr. Chairman and Members of the Committee. Thank you for inviting me to testify today.

My name is Brent Smith. My exposure to the dialysis industry began in 1973, two weeks before my 18th birthday. A year later, I received my first transplant which was from my mother. Two months later, the kidney failed due to infection, and I returned to dialysis. In 1977, I received a second transplant from my grandmother. That transplant succumbed to complications in 1990. I returned to dialysis in the fall of that year. Soon after, it became all too clear that the entity providing treatment, its administration, the support staff, and many of the standard procedures with which I was familiar had changed drastically.

Over the last ten years, as a patient, I have witnessed the gradual decline in competency of those given the responsibility of my care. In my view, efficiencies intended to enhance the financial position of the providing companies expose patients to great risk and may even hasten their demise. This trend continues and worsens each years as providing companies focus on bottom line management and not patient care.

The major concerns of dialysis patients fall within the following five interrelated components. I have provided more detail in a longer statement submitted for the record. They are the following:

- Adequacy of dialysis
- Competency of patient care technicians
- Knowledgeable and disciplined nursing staff
- Facilities and technology (machines)
- Accountability

Adequacy of Dialysis

The adequacy of my prescribed treatment relies heavily on me, my discipline with regard to diet and fluid restrictions, and my oversight of my dialysis treatment. Because I am very disciplined in my care, I can allow the dialysis machines to do their work. I have worked to become very knowledgeable in what is needed for my care. Other patients who are less familiar with the dialysis process are very vulnerable.

One of the areas that needs to be addressed by research is adequacy of dialysis. I can only tell you my personal experience with the amount of time I dialyze. When I dialyze four hours each session, I feel better. When treatments have been shortened in the past, over time my energy levels are depleted. In addition, complications appear from fluid retention, such as higher blood pressure and shortness of breath. I, and other patients, feel lethargic and have little appetite. So, I can only conclude that the amount of time on dialysis is a factor.

Competency of Patient Care Technicians

Second, in the year I started dialysis, the care givers were mainly nurses from the top graduating classes, as well as medical students, and other medical technicians. Almost every technician had a college degree, and every technician had previous medical experience.

Today, I see technicians with only a high school diploma. In Arizona, a manicurist is subject to more licensing than a dialysis technician. When I first returned to dialysis, I had technicians handle my blood and my life who were convicted criminals, strippers, and refrigerator technicians. The ratio of patients to technicians, at times, is now 5 or 6 patients to every technician. This is not safe, and it doesn't work.

A main worry for dialysis patients is vascular access. A patient told me recently of a treatment where it took eight attempts by technicians to initiate her treatment - eight sticks by 16 gauge needle! Not only is this painful, it increases the risk of infection and could destroy that access. There are limits to vascular access with each patient. When vascular access runs out, a patient can no longer dialyze and can die. Many other patients have told me of similar occurrences. These examples, involving poorly trained, unsupervised technicians include the following:

- target weight miscalculations that could cause blood pressure decline. On one occasion, staff miscalculated the projected amount of fluid to remove from me by a significant margin. When this happens, a patient feels extremely weak and lightheaded at best. At worst, a patient can severely crash, losing consciousness with a blood pressure far lower than levels needed to maintain life. Also, patients experience excrutiatingly painful cramping, and treatments will be shortened because the patients cannot withstand additional treatment.
- too much or too little heparin, the blood thinning agent. Too much heparin thins the blood and could lead to the patient's inability to clot blood; so they could bleed to death. Too little heparin allows the blood to clot in the machine and stop the flow of blood back to the patient.
- placement of a dialyzer on the wrong machine for the wrong patient. This is a potentially fatal error.
- Disregard for the Universal Antiseptic Code, the protocol that protects both patient and technician alike from infectious germs, viruses, and bacteria. This is one of the largest and most common reasons patients are hospitalized.

Another example of the training deficiency among dialysis technicians stems from my personal experience. In 1994, I suffered an extended period of appetite and weight loss. As part of my routine assessment prior to each dialysis session, I explained that I had not been eating properly. I reported this for almost four months. The food I was eating did not provide me with sufficient potassium for my prescribed potassium bath. During the fourth month, during the third hour of a four hour treatment, I suffered a cardiac arrest attributable to the low potassium in my system. The attending technician did not recognize this problem. Another technician took over to attempt resuscitation until the paramedics arrived. Upon arrival, Emergency Room records reflected a potassium level of 2.9, well below the 3.5 recommended range. Discharge Summary records showed fibrillatory arrest, secondary to hypokalemia, which is low potassium. The dialysis technician did not correlate the loss of my appetite with the low potassium bath. The seriousness of the problem and possible results were never brought to my attention or to the attention of the charge nurse, the dietitian, or my physician. THIS EVENT WAS COMPLETELY PREVENTABLE.

Knowledgeable and Disciplined Nursing Staff

In addition to competency and training of dialysis staff, I believe that the staff must be knowledgeable and disciplined. I have witnessed instances where floor nurses lacked familiarity with the machines and their functions. These are complicated machines that stand between life and death of dialysis patients. Lack of knowledgeable staff exposes patients to dangerous circumstances. Moreover, lack of discipline or failure to PAY ATTENTION is a primary source of incidents, affecting patient care. On one occasion soon after my return to dialysis, staff drained off too much fluid from me during dialysis. This exposed me to a crash in my blood pressure and loss of consciousness. I am aware of another instance where a patient bled to death, because no one was watching, while the patient's blood inadvertently drained into a trash can while the patient slept. It is instances like this that cause me to do everything in my power to stay awake throughout my four hour dialysis and try to watch every move of the staff attending me and to watch the fluctuations on the dialysis machine.

Facilities and Technology (Machines)

Not all facilities where I have dialyzed have been well maintained. Too often poorly trained or overworked staff will choose speed over substance in attending to patients. Worn, older, overused machines are not as effective and efficient. One problem in dialysis is the way dialyzers are reused. Even though they are labeled for "single use only" many are reused in this country as much as 30-50 times. I do not reuse dialyzers. However, as a patient advocate of many years, I have observations and experiences with regard to reuse of dialyzers from other patients. The efficiency of the dialyzer can decrease as much as 20% over the span of reuse. In turn, it is as if the patient's treatment time has been reduced by 20%. No adjustments are ever made to compensate for this loss. As a result, the patient's lab reports get worse as the patient's condition gets worse. Moreover, many patients aren't aware that they don't have to reuse dialyzers and that the mortality level is higher with reuse. I know of one woman who could only reuse eight times before she felt very bad.

In addition, I have been told by staff that Medicare pays for a new dialyzer after each session. However, my experience is that dialyzers are used as much as 30-50 times. In fact, facilities have had to establish elaborate procedures to clean, sterilize, and catalogue dialyzers to ensure that patient receives their own dialyzer during sessions. I am aware of one technician who processed one patient's dialyzer bar code and passed and approved all other patient bar codes on that basis. This violated the procedural rules and, of course, exposed patients to potential harm.

Accountability

One of the most important aspects of patient care relates to their relationship with the dialysis staff. Staff must be accountable for the level of care provided to patients. They must demonstrate strict adherence to set policy and procedure. Appropriate discipline must be administered for breach of policy and procedure. This is a life or death situation. In my experience, technicians are rarely written up for minor or major infractions, involving patient care. I have seen technicians abuse the glove policy, exposing patients to possible infection. I have seen technicians reading magazines while on duty rather attending to patients. I have seen technicians engage in distracting conversations when inserting or removing needles from people.

In all my years on dialysis, I have never seen a government surveyor review a facility where I have dialyzed. In fact, I am unaware of any surveys of any facilities where I have dialyzed. I am greatly concerned as a dialysis patient about oversight of this industry.

In closing, throughout my life I have strived to avoid the label, "dialysis patient," and the stigma associated with it. Yet, today I appear before you, in the public forum, as a dialysis patient, because of the importance of the issues being discussed here today. Patients can and do lead productive, purposeful lives. However, it has become an increasing burden to do so. Monitoring a technician's abilities during every treatment, week after week, is a tremendously stressful undertaking for a dialysis patient. Enduring the limits and inadequacies of the present system of dialysis compound the already difficult treatment into an intolerable, unjustifiable, and inexcusably frustrating experience.

My purpose today in appearing before this committee was to present the life of a dialysis patient to you. It is my life, and that of many others. We live it every day. You cannot possibly understand it. I sincerely hope you or a loved one will never experience it, but I do implore you to do something about it.

Thank you.